

University of Groningen

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Dealing with data protection in research

[Esther Hoorn](#), a legal adviser at the University of Groningen, explains the problems universities and researchers have to contend with in data management and protection. A 'maturity model' used to improve business processes may help.

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There are two major issues for universities to contend with at present. The open science agenda that requires researchers to publish their findings openly and the upcoming European General Data Protection Regulation (GDPR) that universities are supposed to comply with from May 2018.

People are struggling to keep up with all the changes. [A recent Austrian study](#) showed 45 per cent of researchers wanted legal advice on open science. In particular, they were worried about the tension between open science and the risk of re-identification from the data they use in their research.

A learning model

The GDPR is supposed to enable research rather than restrict it and it has room for exceptions based on ethical codes. But the [ethical codes for data-intensive research](#) are still under development worldwide, so we need a learning model.

We need a thorough assessment to address the data protection issues and to define practical, organisational and technical measures. To achieve this researchers, lawyers and IT professionals need to work together to design measures to take into account the rights of the data subject in the context of research.

I have experience in data management, legal and ethical issues. By collaborating with Marlon Domingus, research data management program manager at Erasmus University Rotterdam, I learned about maturity models from the CMMI Institute. They can help structure change from random to structured to policy-

driven. In turn, Domingus learned about self-regulation in the General Data Protection Regulation.

[Marlon Domingus' maturity model](#)

Domingus' maturity model provides a structure to work with, allows researchers and research managers to share their ideas and helps give direction. It covers various stages of development: initial, repeatable, defined, managed and optimised. It also describes what the stages mean for various interested parties in a university setting: across the university, faculty, legal, chief information officer, and IT.

The model could be used as a guide to develop or adopt a strategy, to move from one level to the next, and to do so collectively within your university.

Data management plans

A few years ago the European Commission started the open research data pilot asking researchers to create a data-management plan within the first six months of a research project in specific calls. While this is not formally assessed, the open research data pilot is becoming a default policy.

As a lawyer looking at how the data-protection measures are implemented, this is interesting because now all projects need to have data-management plans.

With the open-science agenda, the idea is that researchers should make their data as open as possible. Researchers can feel torn between being open and taking into consideration the data protection, as well as the intellectual property, issues involved.

Among the first calls experimenting with open data, there were no human-subject research calls, so the evidence about what the real issues might be when you have personal data have not been really identified yet.

According to officials at the Directorate-General for Research and Innovation, the first data management plans involving human subjects from health-related research actions are due next spring.

All change

In Europe, the regulation on data protection that will come into effect as of May 2018—the General Data Protection Regulation—has exceptions for research.

Some observers say that not much will change for research but there are some new instruments such as 'privacy by design' and data protection impact assessments (DPIA) designed to assess, at an early stage, what measures

researchers and their institution should take to safeguard the interests of participants, including informing them about their rights and more transparency.

There are two remarkable things about the regulation.

1. It is deliberately written in a technology-neutral way, because by tomorrow any particular technology is likely to be out of date.
2. It requires the data controller to demonstrate compliance; the legal entity that decides on the means and motive for processing personal data, (such as the board of Google or Facebook, for instance).

In universities, the research culture has always been that the researcher has to assess the risks in using data and how the research should be done, so there is a gap, or tension, in how to implement the regulation within a research setting.

Research by definition is a collaborative enterprise so you need to have trust between the partners and the requirement to determine in a transparent manner the shared responsibility.

There is a possibility for derogations (relaxation or exemptions) for research based on the principle of data minimisation and purpose limitation, but it needs collaboration at a European level to align this for research collaboration in all member states and work out how it will apply to research.

It's really important to agree that we need a learning process. For us, the research community needs some space to comply with the GDPR and the requirements in the ethical review procedure aligned to the European Research Council grants. Those researchers are guinea pigs being asked how they will demonstrate awareness of data protection risks now and if their research complies with the upcoming GDPR.

The DPIA and the maturity model are really helpful to decide who will be responsible for what within a host institution and how to assess, on a discipline or research project-specific basis, what measures are needed.

How it works at Groningen

We are now carrying out consultation sessions on how to tackle the ethics self-assessment part of Horizon 2020 applications, which can have dedicated training or even DPA as a deliverable in the data-management plans. We are actively trying to support completing the ethical assessment as a learning process.

For example, in Groningen, the formation of the Data Federation Hub enables

researchers to tackle the whole data life cycle challenges of research data with a synergy of expertise, support and facilities sharing lessons learned and best practices. Under this umbrella, the Human Subject Research programme we are working on a translation of a German data protection impact assessment from Harvard University's privacy tools project [datatags](#).

In [the Dutch Draft code of conduct for personal data in research](#), which puts emphasis on doing a data-protection impact assessment is a central instrument (please note proposed standard research scenarios and measures are in English). The responsibility for data protection is shared between the researcher, the dean responsible for research policy, and the board that has to facilitate the infrastructure for research.

There is also a recent declaration on the European open-science cloud that states that researchers' host institutions are responsible for overseeing and completing data-management plans and handing them over to data repositories. This is something that needs to be elaborated upon within institutions.

Getting started early

The early bird catches the worm. It's a good thing to help researchers to assess these risks and measures at an early stage.

Using the method of a DPIA can help researchers assess where things need to be developed, for instance, with a pseudonymisation service (to help keep data private) or how to integrate privacy by design in research projects.

This ambition for open science is here to stay. Researchers need to start asking for advice earlier. Go to the research office in the first instance and they will direct you.